



## **ASPHO 2021 Legislative Priorities**

The American Society of Pediatric Hematology/Oncology (ASPHO) is a multidisciplinary organization representing more than 2,000 members dedicated to setting, advocating for, and achieving the highest standards of care for children, adolescents and young adults with cancer or blood disorders and their families.

### **Childhood Cancer STAR Act Funding and Implementation**

**Support full funding for the Childhood Cancer STAR Act (P.L. 115-180)** – The Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act — the most comprehensive childhood cancer bill ever taken up by Congress — was signed into law on June 5, 2018. The law expands opportunities for childhood cancer research, improves efforts to identify and track childhood cancer incidences and enhances the quality of life for childhood cancer survivors. **ASPHO urges Congress to appropriate \$30 million in Fiscal Year (FY) 2022 to fully fund the Childhood Cancer STAR Act.**

### **Funding for Cancer Research Programs**

**Continued funding for the Childhood Cancer Data Initiative (CCDI)** – The CCDI is a dedicated federal investment of \$50 million proposed to be extended annually for the next 10 years, with the first year of the initiative funded in December 2019. These funds will allow the National Cancer Institute to establish more efficient ways to share and use childhood cancer data. **ASPHO urges Congress to appropriate \$50 million in FY 2022 to continue the CCDI.**

**Increase funding for the Peer Reviewed Cancer Research Program and Support the Inclusion of Childhood Cancer Topic Areas** – Childhood cancer affects families regardless of geographical location, occupation, or income, and impacts military families without prejudice. Cancer is tragically the leading disease killer of children, adolescents and young adults in the United States, with brain tumors being the leading cause of cancer death in children ages 0–19. The Peer Reviewed Cancer Research Program (PRCRP) at the Department of Defense funds vital research to enhance our understanding of deadly tumors and more broadly cancer in children, adolescents, and young adults so that treatments can be more effective and less harmful to children. **ASPHO urges Congress to once again extend PRCRP eligibility in FY 2022 to pediatric brain tumors, brain cancer neuroblastoma, as well as cancer in children, adolescents, and young adults. Further, we urge Congress to support \$130 million in funding for the program in FY 2022, a \$15 million increase.**

### **Funding for SCD Programs**

**Increase funding for the CDC Sickle Cell Data Collection Program** – Sickle cell disease (SCD) is an inherited blood disorder that affects an estimated 100,000 Americans, with the burden falling predominantly on people of color, particularly individuals that are Black or African American and Hispanic American. Individuals with the disease produce abnormal hemoglobin which causes severe pain and can lead to strokes, acute chest syndrome (a condition that lowers the level of oxygen in the blood), organ damage, and in some cases premature death. The Centers for Disease Control and Prevention's (CDC) Sickle Cell Data Collection Program supports states in the collection and analysis of population-based surveillance data to gather information on the prevalence of SCD and health outcomes, complications, and treatment that people with SCD experience. **ASPHO urges Congress to provide \$5 million in dedicated funding for the CDC Sickle Cell Data Collection Program in FY 2022, a \$3 million increase.**